
The Status of Health Information Delivery in the United States: The Role of Libraries in the Complex Health Care Environment

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ABSTRACT

DISSEMINATION OF HEALTH INFORMATION is governed by complex social issues, structured pricing, and information technology. Factors comprising a new paradigm for examining Consumer Health Information (CHI) are presented. The provision of CHI services in libraries (public, academic, hospital) and services provided by health information networks are described in relationship to specific programs. Problems related to the provision of information services are outlined. Outcomes of the Raven Study which provided baseline data for understanding early CHI networks including a description of the "Utopian Health Information Network" are summarized. Print and electronic current awareness resources have been included as an appendix.

INTRODUCTION

Public health issues in the United States can trace their beginnings to a law passed in 1798 to provide for the "care and relief of sick and disabled seamen." Concerns were largely limited to the health of merchant seamen and the prevention of disease epidemics. In 1912, this service formally became the Public Health Service (PHS) with functions expanded to include biomedical research, regulation of health products in interstate commerce, and studies of environmental hazards. The dissemination and delivery of health information to the public and the role of libraries in this endeavor is less clearly defined. In fifteen years, libraries have experimented

with demonstration projects and innovative services but have not integrated health information into the mainstream library programming.

This article discusses the current environment in which health information is disseminated; components of an emerging paradigm affecting the dissemination of health information; the status of libraries and library networks in distributing such information; and problems of delivering health information. Suggested current awareness resources available to enhance library collections have been appended to the article.

HEALTH INFORMATION VERSUS PATIENT EDUCATION

Health information is of two types: (1) information needed to make informed decisions related to disease prognosis (patient information), and (2) information needed to support a healthy lifestyle (consumer health information). Often these terms are used interchangeably. In the United States, patient information is produced by organizations affiliated with conditions and diseases, for example, cancer (the American Cancer Society). Information supportive of healthy lifestyles is primarily produced and distributed by the PHS.

Consumer Health Information (CHI) is a broad term which refers to aspects of a healthy lifestyle and implies improved knowledge and understanding of one's own personal health. If the knowledge and understanding changes the person's behavior (e.g., smoking cessation), an educational process takes place. Consumer health education is a process that informs, motivates, and helps people adopt and maintain healthful practices and lifestyles (Fogarty, 1976). A later definition describes health education as a strategy to "bring about voluntary adjustment of behavior conducive to health" (Green, 1978). While attainment of a minimum base of information is required before a health education strategy can be adopted, behavior change requires more than health information. Green also raised information policy issues and warned about health information fallacies: equating information *giving* with information *utilization*. This theory includes the notion that anything is better than nothing; more information is necessarily better; exposure can be equated with impact; and what motivates some will motivate others. How and where information is communicated is also a factor. To be effective as a part of health education, information must be transmitted locally where the sources of information are more trusted (local radio and television, for example, allow for variation, clarification, and adaptation). The idea is that information disseminated locally results in active, rather than passive, behavioral change.

Patient education is a well-defined term implying that a person has a sickness or disease and needs to be educated about the condition. Most hospital-based information services are designed to react to the patient's need for information rather than fostering a proactive approach to improved lifestyle. As individuals take more responsibility for making decisions related to their own health care, a new paradigm is being created through which CHI can be examined.

A PARADIGM FOR EXAMINING DELIVERY OF CHI

The emerging paradigm for communicating and disseminating consumer health information includes the following factors:

- proactive government and industry health care initiatives;
- structured financial transactions have forced individual health care decision making;
- information is a commodity;
- limited aggregated information resources are accessible to empower the consumer to make intelligent choices;
- communication governs informed consent;
- libraries are a nonthreatening, inexpensive channel through which health information can be distributed;
- an aging society has multidisciplinary information needs;
- improved mechanisms for translating research summaries, abstracts, and results into popular formats are needed;
- information technology can improve access and decision making (half of these factors were previously identified [Rees, 1992], others were added by the author).

Proactive government and industry health care initiatives. Healthy People 2000 is a national initiative to improve the health of all Americans through prevention. It is driven by 300 specific national health promotion and disease prevention objectives targeted for achievement by the year 2000. Healthy People 2000's overall goals are to increase the span of healthy life for Americans, reduce health disparities among Americans, and achieve access to preventive services for all Americans. Progress reports and updates are published for program planners and educators. The Office of Disease Prevention and Health Promotion (ODPHP) collects and reports prevention activities related to the nation's health promotion and disease prevention objectives. Progress of committees attached to this initiative, such as the National Coordinating Committee on Clinical Preventive Services, is reported in *Prevention Report*, an ODPHP administrative publication that is not made available through general distribution. Reports and updates are in the public domain and can be easily reproduced by libraries for distribution to the public.

U. S. companies have increasingly recognized that working too many hours a day can result in burnout. A two-year study by Minneapolis-based Northwestern National Life Insurance Company found that the best low-stress workplace had open communication, flexible leave policies, and competitive benefits. Many had adopted wellness programs. Health clubs, hospitals, and adult-education centers also offer stress reduction programs. The American Institute of Stress (Yonkers, New York) and the American Institute for Preventive Medicine (Farmington Hills, Michigan) are good sources of recognized programs. The Health Insurance Association of America (Washington, D.C.) has actively promoted "wellness at the worksite" for more than ten years.

Structured financial transactions have forced individual health care decision making within a complex health care environment. Accelerated costs and complex reimbursement schedules associated with traditional medicine have created a demand for health information resources which have not traditionally been a part of library collections—e.g., the volumes of analyzed Medicare data related to coverage and limitation of hospital services. Under traditional fee-for-service health insurance plans, doctors and hospitals are paid regardless of the services or tests they perform. Over the past two decades, costs have accelerated from 7.3 percent of the Gross National Product (GNP) in 1970 to 13.4 percent in 1992; it is projected to reach 16.4 percent in 2000 or \$6,616 billion (Faltermayer, 1992). Faltermayer also describes five paths to universal health insurance.

The two primary government-financed programs, Medicaid (for the poor) and Medicare (for those 65 or older) already exceed price ceilings—including a new 7,000 item revision in what doctors can charge for treating the elderly. In addition to regular visits to doctors' offices in 1990, Americans made an estimated 425 million visits to nontraditional providers of therapy, such as those who administer acupuncture and chiropractic treatments. Expenditures associated with these visits amounted to approximately \$13.7 billion (Eisenberg et al., 1993). Cost as a factor in patient decision making is just beginning to make an impact, especially for large purchasers of health care.

Cost and reimbursement information, such as that contained in the *Medicare Provider Reimbursement Manual*, is constantly being updated (HCFA-Pub. 15-1 thru Rev. 353, January 1990) and is often processed in libraries months after being issued (this particular item was processed by the University of Illinois at Chicago [UIC] Library of the Health Sciences [LHS] on March 14, 1991). The difficulty in disseminating this type of information lies both in locating and

retrieving the document. For the consumer, the problem is further complicated by technical language and the lack of interpretive summaries. Although these resources do exist, they are difficult to locate and no evaluative guidelines exist to assist patrons in filtering the literature.

Information is a commodity. A positive correlation between information and satisfaction and between satisfaction and compliance has been described (Rees, 1993). Benefits of improved information dispensing for the patient include refined articulation of questions to determine health concern, enhanced dialogue between patient and doctor to improve medical history taking, greater understanding of risks and rewards, improved therapy compliance, and, in the end, greater satisfaction with decisions made. Benefits of improved information dissemination for the well person include more productive and independent lifestyles.

Limited aggregated information resources to empower the consumer to make intelligent choices in choosing health care or resolving conflict. The absence of a central system to coordinate the dissemination/integration of existing information creates confusion and limits access to information. Data accumulated by government agencies should be made available in more meaningful formats. Health is the primary mission of the PHS, and its principal components—the Food and Drug Administration (FDA); the Centers for Disease Control (CDC); the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); the Health Resources and Services Administration (HRSA); and the National Institutes of Health (NIH). NIH, with its seventeen institutes and affiliates, serves the public through its information arm, the Office of Disease Prevention and Health Promotion (ODPHP). Each institute also has an information officer to deal with public requests and facilitate communication among institutes. The federal government, directly or indirectly, generates by far the greatest volume of consumer health information and generally disseminates such information via mail or telephone hotlines.

Federal agencies support at least thirteen information clearinghouses that distribute information related to diseases and health care conditions. A listing of these clearinghouses is available through the ODPHP. Designed for distribution to the public, these materials are usually in the format of fact sheets (one- or two-page statements about specific diseases and their treatment, care, or prevention); booklets that describe diseases in a more comprehensive way and indicate what can be done to help patients; and research reports which, even when adapted for public use, may be difficult to understand.

Adding to the confusion of government parceling of information is the creation of new information centers and clearinghouses by private industry. An example is the National Vaccine Information Center in Vienna, Virginia. A half century ago, the bacterial ailment known as whooping cough killed up to 7,000 people a year in this country. Although fewer than ten have died annually since 1981 according to the CDC, the vaccine introduced in the 1940s contains a dead pertussis cell that fosters antibodies to fight the disease. This cell also carries a neurotoxin that can cause side effects, swelling, fever, or high-pitched crying. Parents, doctors, and drug makers reported about 7,200 adverse reactions and 250 deaths after pertussis vaccinations for the twenty months ending July 31, 1992 ("Thousands Sue Over Effects of Major Vaccine," 1992). Immediate retrieval of information related to side effects is crucial in determining subsequent health actions. Only a morphogenesis interconnecting a vast network of clearinghouses and information centers using computer visualization will enhance retrieval of specific information.

Another source of confusion for the consumer is obtaining early reports of ongoing research. Immediate applications of new knowledge to disease states are not always communicated in meaningful ways. A report published by the National Commission on Orphan Diseases (U.S. Department of Health & Human Services, 1989) describes the difficulty patients with diagnosed orphan (rare) diseases have in obtaining information to assist them in making decisions. Not only could patients not find needed information, but in documenting physician access to information, nearly half of the 247 physicians studied could not find printed information for their patients, and more than one-third could not find information summarizing ongoing research (U.S. Department of Health & Human Services, p. 18). If library collections were enhanced to include resources on rare diseases for practitioners and their patients, or if requests could be adequately referred, this problem could be ameliorated.

Communication governs "informed consent." Informed consent has become an integral part of health care decision making. During the 1980s, topics reflected treating minor children without parental consent, medico-legal matters, and right to know issues. Discussions of the 1990s include the right to refuse medication, liability issues related to dementia and AIDS, uses of human tissue, and mental competency. The dialogue regarding consent that does or does not take place in the doctor/patient encounter has a direct relationship to the ethical and legal interpretation of medical regulations. Informed consent preserves two values, self-determination and personal well-being (Hollander, 1984). Individual well-being in the

philosophical sense includes personal values and preferences, and choice often includes compromise. Communicating probabilistic information to patients is vital knowledge to those making decisions.

Although hospital libraries are positioned to disseminate needed information to patients and their families, many hospitals continue to restrict access to professional library collections. Hospital libraries were first established to support their physician staff and then evolved as a support service for all professional staff. Subsequently, collections and services were developed to educate the professional staff. Few progressive services developed during the past fifteen years remain in existence. The question could be raised as to why more hospital libraries have not become cost centers given that information is a commodity and is vital to decision making.

Libraries are a unobtrusive inexpensive channel through which health information can be obtained. Because health information comes in all sizes, shapes, and with little or no frequency, it is difficult to maintain and manage. At the present time, health information resources are intermittently produced on topics in a variety of print and electronic formats, and access is fragmented. These resources are usually not indexed, nor are they regularly updated. If central or regional repositories maintained CHI resources on a LISERV, information could be easily distributed through library networks. Libraries have experience in creating electronic records and authority files, assigning subject headings, and providing annotations and cross references to other resources. Selected documents in the public domain—such as reprints from *FDA Consumer* on safe use of medicines, arthritis, stroke, generic drugs—could be scanned into a relational database for use by the public and would be an ideal library project.

Libraries can assist patients and consumers alike in scripting specific questions to be asked, refining aspects of those questions, or providing options for expanding queries. Such preparation could result in more efficient use of time in a typical office or telephone encounter. Libraries are acceptable vehicles for disseminating information produced by federal, state, and local governments. They could also serve as depositories for information produced by associations, foundations, and private industry. In conclusion, health information that libraries provide is a cost-effective way for consumers to gain understanding of a given condition prior to making decisions.

Improved mechanisms for translating research summaries, abstracts, and results into popular formats. Paul Elwood of InterStudy (Minneapolis Research Organization) believes future computer databanks will track patients medically. InterStudy currently studies sixteen illnesses such as diabetes and hypertension. To date, 20,000

patients in twenty-three states have completed a survey intended to identify individual health views, such as, "does your health limit you in climbing several flights of stairs."

Only three years old, the Agency for Health Care Policy and Research (AHCPR) has a budget of \$74 million (1993) to study guidelines for treating disease. AHCPR finances twelve "patient outcomes research teams," which assess medical outcomes and technologies primarily based on reviews of the literature (not new research). Guidelines have been issued on four conditions—pain control after surgery, control of urinary incontinence, control of bedsores, and treatment of cataracts. Guidelines are unique, as they are summarized for both the health care professional and the patient. Libraries are positioned to make guidelines available as part of print collections (reprints or pamphlet files) or accessible electronically in summary or full-text format.

Longitudinal research, such as the Framingham studies, Baltimore Longitudinal Study, and the Alameda County studies, are ongoing projects which measure physiological and psychological functions and report risk factors that alter lifestyle. Risk factors described in the literature include personal habits, nutrition, exercise, cholesterol intake, or demographic and genetic characteristics. Findings of these studies appear as reports by the supporting government agency. Few are written in popular style or in a manner to change behavior. Health sciences libraries are in an ideal position to repackage research summaries for consumer understanding.

Multidisciplinary information needs of an "aging society." Two factors that will affect the information needs of an aging society are few research studies on which to evaluate treatment of older adults, especially older women, and the absence of integrated information treatises to illustrate how lifestyle interacts with therapy (e.g., medication). Preventive measures taken early in life have always been an acceptable way to defer or prevent chronic diseases or functional problems encountered in later life (Stults, 1984). Only recently has society directed health promotion initiatives at persons already old. Despite the wide availability of communication technology and assistive devices to improve safety and quality of life, the average older person lives without using any of them. Lack of research funding to evaluate such devices, limited reimbursement, inadequate knowledge of health professionals to match products with individual problems, and inadequate translation and delivery of knowledge about such products impede their use and understanding. Libraries with access to databases, such as ABLEDATA, help diffuse this information. Although health professionals are beginning to recognize the need to include older persons in activities aimed at

preventing disease and reducing disability, there remains a serious lack of scientific data to direct change. Agencies producing and distributing information related to seniors' health are the National Institute of Aging (NIA), the American Association of Retired Persons (AARP), the National Council on Aging (NCOA), the Food and Drug Administration (FDA), and the Food and Nutrition Information Center (FNIC), one of ten information centers administered by the National Agricultural Library. Only large academic and public libraries that are government depositories are likely to routinely collect reports and documents produced by these agencies. Rarely do these materials reside in health sciences libraries.

Working with state departments on aging, libraries can assist patrons in finding local resources and structure referral services to satisfy the multiple aspects of requests related to the elderly. Redesigned user-friendly reference tools are needed to support the interdisciplinary information needs of the elderly. Needed tools include directories of care providers, manuals describing housing and transportation alternatives, and access to improved information networks to reach the ever-changing governmental and state guidelines.

Impact of information technology in improving access and decision making. Information stored and distributed in electronic form provides additional avenues through which CHI can be disseminated. Avenues include databases, CD-ROM products, and bulletin boards. Databases contain bibliographic, full-text, or summaries of documents. They are produced and maintained by major vendors, such as BRS, DIALOG, and the National Library of Medicine (NLM). Examples include NLM's DIRLINE, an online directory of health care associations, and BRS's National Newspaper Index. Concerns about drug interactions and recalls, legislation, and new medications under development are contained in FDA's Bulletin Board. As the Internet becomes more accessible for institutional use, LISTSERVs are popular vehicles to communicate the existence of health resources. For example, PDQ, a database containing information about cancer treatment produced by the National Cancer Institute, is available through the Internet as Cancernet. Information in PDQ is reviewed by cancer experts and provides up-to-date information for people with cancer, their families, and for doctors and other health care professionals. PDQ includes information about research on new treatments (clinical trials), a directory of doctors who treat cancer, and hospitals with cancer programs.

Newspapers provide the first line of communication for reporting information about AIDS, cancer, heart disease, respiratory ailments, and epidemics, such as Legionnaire's Disease. Brief summaries of

research studies and surveys frequently appear in newspapers before articles appear in the journal literature. A logical progression of further inquiry is illustrated in Figure 1. Electronic tools accessing newspapers include: *VU-Text* (covers Knight-Ridder newspapers from 1983 to date); *National Newspaper Index*, accessible through BRS, which covers selected newspapers—e.g., *The Wall Street Journal* and *The New York Times* from 1979 to the present; national and international sections of *The Washington Post*, and *The Los Angeles Times* from 1982 to present; and *File Papers* (accessible through DIALOG), a more comprehensive listing of newspapers. A sample search (nutrition and the elderly) retrieved 1,585 references in 1991.

There are a number of CD-ROM products available. *Health Periodicals Database* is a recently developed hybrid database directed at the layperson. It covers all aspects of health, medicine, fitness, and nutrition. Abstracts are “consumer summaries” from about 100 professional medical journals, and full text is available for approximately 120 professional and consumer health publications (Tenopir, 1992). *Health Index Plus*, a part of *InfoTrac* (Information Access Company), contains about 130 professional and consumer publications on medicine, public health, disease, occupational health and safety, nutrition, and fitness. Full-text articles from over eighty publications and consumer-oriented summaries of key scientific papers translated by medical professionals are contained in the product as well as health-related information from about 3,000 general magazines and newspapers. *Health Index Plus* is updated monthly and contains about four years of information (Alloway et al., 1992). *Medical Data Exchange* (MDX) is a CD-ROM product offered by SilverPlatter, Inc. The file contains summaries of current articles on health issues from 37 medical journals from MEDLINE and includes about 200 other consumer publications, including wellness newsletters. Additional CD-ROM health care reference products, including *The Family Doctor* (Creative Multimedia Corporation), *PDR (Physicians' Desk Reference)* with the *Merck Manual* (Medical Economics Data), and *Scientific American Medicine* (Scientific American Medicine) have been reviewed by LaGuardia (1993).

ROLE OF LIBRARY PROFESSIONAL ASSOCIATIONS

Library associations, such as the American Library Association (ALA) and the Medical Library Association (MLA), have traditionally assumed roles for continuing education of librarians. At one time, ALA responded to such issues within the Library Service to Special Populations Section (Cooperative Library Systems Division). Health information is the topic of a roster course within the MLA Continuing Education platform. MLA also supports a section dedicated to

CONSULTATION



BY JAY SIWEK, M.D.

Fibroids in the Uterus

Q. I have a fibroid on my uterus, and my gynecologist recommends that I have a hysterectomy because of its size. It's not giving me any problems, but he thinks it would be best to have it out now while I'm still healthy. I'm 48. Are there any guidelines about when surgery is needed for fibroid tumors of the uterus? Couldn't I just live with it and reconsider surgery if it started to bother me in some way?

A. There are a few good studies that give solid answers to your question. But in general, I think you have some flexibility in deciding about surgery. A fibroid is a benign enlargement or growth of the muscular tissue of the uterus. Its size may range from as small as a golf ball to as large as a softball or even a soccer ball. Fibroids are common. About one in four women over 30 have one...

As with an elective operation, if you have some questions about whether it's worth having, getting a second opinion can help. Two recent medical articles discussing indications for hysterectomy are in the March 1993 issue of the *American Journal of Obstetrics and Gynecology* and the March 25, 1993, issue of the *New England Journal of Medicine*.

WASHINGTON POST HEALTH SECTION, TUESDAY, APRIL 6, 1993, P.15

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Oldenhave A et al (1993). Hysterectomized women with ovarian conservation report more severe climacteric complaints than do normal climacteric women of similar age.

RESULTS: Hysterectomized women, especially those aged 39 to 41 years, report significantly more vasomotor complaints, vaginal dryness, and atypical complaints than do normal climacteric women of the same age. The higher prevalence of typical climacteric complaints in hysterectomized women largely explains their higher level of atypical complaints.

CONCLUSION: Physicians should be alert to typical climacteric complaints after hysterectomy with ovarian conservation, especially in young women, because the literature indicates that hysterectomized women with ovarian conservation are overrepresented with regard to osteoporosis, cardiovascular disease, osteoarthritis, depression, and sexual problems. (*Am J Obstet Gynecol 1993;168:765-771*)

Figure 1. Logical progression of information query

consumer health issues. Within the Special Libraries Association, selected divisions have health-related concerns. Examples include chemistry, food, agriculture and nutrition, and pharmaceutical.

In 1979, a CHI continuing education course was developed by Rees for the MLA. Course objectives emphasize trends in medical consumerism, design and development of health information programs in a variety of settings, and the creative applications of library cooperatives in the provision of CHI. The number who have attended this course is estimated to be about one-fourth of the MLA

New Engl J Med 328(12):856-859

Carlson KJ, Nichols DH, Schiff J (1993). Indications for hysterectomy.

INTRODUCTION: Hysterectomy is second only to cesarean section as the most frequently performed major operation in the United States. Data from the National Hospital Discharge Survey (NHDS) indicate that approximately 590,000 hysterectomies are performed annually. Although there appears to be a downward trend in the rate since the mid-1980s, it is not yet known whether a true decline has occurred, because there have been recent changes in the NHDS sampling method. By the age of 60, over one third of U.S. women have undergone hysterectomy. The annual hospital costs for the operation currently exceed \$3 billion. . . .

New techniques of performing hysterectomy and new alternative treatments have been developed in recent years. This review examines the indications for the operation, considering current knowledge of the benefits and risks of hysterectomy and alternative treatments, costs, and the importance of the patient's preferences in the treatment decision. . . .

Self-Help Organizations*

Hysterectomy Educational Resources and Services Foundation
422 Bryn Mawr Avenue
Bala Cynwyd, PA 19004
(215-667-7757)

The HERS Foundation has a number of publications on hysterectomy, post-hysterectomy, and common pelvic disorders. A reading list is available for \$3.00. The quarterly HERS Newsletter contains an in-depth research article, a review of current scientific journal articles, correspondence, and a calendar of events. HERS is a nonprofit organization founded in 1982 for the purpose of providing information about the alternatives to and after effects of hysterectomy and/or oophorectomy.

Books**

Goldfarb HA, Grief J. *The no-hysterectomy option: your body, your choice*. New York: Wiley, 1990.

Hufnagel V, Golant SK. *No more hysterectomies*. New York: New American Library, 1988.

Payer L. *How to avoid a hysterectomy: an indispensable guide to exploring all your options—before you consent to a hysterectomy*. New York: Pantheon Books, 1987.

*DIRLINE strategy: *Hysterectomy (MH) or Hysterectomy (NW)*

**CATLINE strategy: *Popular Works and Hysterectomy*

Figure 1. (Cont.). Logical progression of information query

membership (or about 1,000 librarians). Since the MLA tracks only courses held at the annual meeting and chapter meetings for the current year, the impact on librarians taking this course compared to other core continuing education courses is not measurable. Experience teaching this course indicates that a significant number of members have reached a basic understanding of the complex issues related to the provision of consumer health information services.

The idea of CAPHIS (Consumer and Patient Health Information Section) as a special interest group of the MLA began in 1981 at the Montreal Annual Meeting. In 1982, the potential CAPHIS section held a meeting attended by more than fifty librarians. In 1984, provisional status was granted, officers were elected, and, by December 1992, the section reported 303 active members.

At the 92nd Annual Meeting of the Medical Library Association (MLA) in Washington, D.C., Alan Rees presented the Janet Doe Lecture, a lectureship traditionally given by a major contributor to health sciences librarianship. In his address, Rees emphasized the importance of communication in the doctor/patient relationship and argued that society has shifted from a physician-oriented to a patient-centered environment (Rees, 1993). The selection of Rees to present this prestigious lecture endorsed the importance of Consumer Health Information by the MLA and the need to identify information access problems. Well-known to librarians for his works, *The Consumer Health Information Source Book* (1990) and *Managing Consumer Health Information Services* (1991), Rees has also raised the awareness of librarians about the provision of health information services to consumers.

NATIONAL LIBRARIES

While not producers of health information, national libraries already share areas of health responsibility, and they are intrinsically tied to the virtual library concept in expanding access to nonprofessional health literature. The National Agricultural Library (NAL) administers ten information centers including the Food and Nutrition Information Center (FNIC). FNIC routinely collects information regarding nutritional requirements and dietary habits for all ages. Bibliographies are selected and evaluated by a team of nutritionists and are distributed upon request. The Library of Congress (LC) administers Resources for the Blind and Physically Handicapped. Given the passage of the Disabilities Act and the multidisciplinary needs of an aging society, the network through which these resources are distributed should be reassessed and expanded for greater effectiveness. Although health information for the public is not part of the mission of the National Library of Medicine (NLM), it currently maintains online directories, such as DIRLINE (directory of health care organizations) and DBIR (directory of biotechnology information resources).

PUBLIC LIBRARIES

In the United States there are approximately 8,900 public libraries ranging from the largest metropolitan libraries in New York City,

Chicago, and Los Angeles to small branches. Public librarians have reported health information access concerns, such as ethics and problems of medical reference and currency issues related to up-to-date medical sciences collections (Powers, 1979; Everhart, 1991). Guides have been prepared to assist public libraries in developing and maintaining CHI collections (Jennings, 1980; Bain, 1984; Rees, 1991). Consumer health pilot projects completed by two New York state public library systems, the Nioga Library System and the Onondaga County Public Library have been reported (Bain, 1984). Projects were designed to distribute information centrally through a health education system.

In an attempt to evaluate how effectively libraries are responding to the needs of the public, researchers at the University of Illinois at Chicago (UIC) have designed a study to evaluate three library pathways through which consumers seek information—public libraries, health libraries (both academic and hospital), and library networks. As part of this project, thirteen large public libraries in the United States and one in Canada were surveyed in December 1992. Preliminary results indicate that large public libraries actively disseminate health information to patrons. Even with recent budget restraints, more than 70 percent of the libraries studied added to their health collections during the first six months of 1992 (Dahlen & Cogdill, 1993).

With the exception of recent Canadian studies, few national studies can be found comparing access to health information with other types of information—e.g., legal, environmental (Marshall, 1991). In 1971, a national survey of library services to the aging was completed by the Cleveland Public Library. Recommendations included special recognition of the aging in library legislation and coordination of services to aging as a discrete program of library agencies.

Literature of the past ten years examines problems by age group (Alloway, 1983); collections and services in single library settings (Defoe, 1991); the scope of information by topic or disease (Powers, 1979); the service (reference) perspective (Berk, 1985); or describes policies and procedures from an administrative point of view. Although collections reflect population health concerns, provision of service is still managed in a haphazard way.

HOSPITAL LIBRARIES

Activities of seventeen hospital-based consumer health centers in the United States have been described (Kernaghan & Giloth, 1991). Many of these programs operate active telephone information services; in fact, some provide only phone contact. Many of these programs are tied to hospital marketing programs. Five hospital-based services

are also described by Rees (1991), including origins, operations, funding, and collections. Two innovative newer programs are those based at St. Joseph's Hospital in Denver, Colorado, and the Planetree Health Resource Centers in California.

The Patient Health Research Library was established at St. Joseph's Hospital in Denver, Colorado, in July 1985. This service has responded to an average of sixty-seven patients per year. Total patrons numbered 540 for a four-year period (1985-1989) including family, friends, and community patrons. The proposal developed to justify support of this service was based on the concept that patients consistently cited inadequate explanation of various aspects of their diagnosis as the most stressful aspect of hospitalization (Volcer, 1977). Planning activities included a patient needs assessment, environment competitive analysis, review of alternative solutions and implementation issues. Bandy provides a case for patients having access to the medical literature. Finding answers to questions about infectious diseases leads to discovery about treatment options, risks, and gives the patient a sense of control in making an informed decision. An item from the consumer collection is supplemented with one from the professional collection. Databases, such as CHID (Consumer Health Information Database [BRS]) or the Disease Database on Development, have been used to satisfy such requests (Bandy, 1991).

The Planetree Health Resource Center is a California-based, nonprofit consumer health organization founded in 1978. Named for the tree that Hippocrates sat beneath when he taught his first medical students, the organization is dedicated to empowering people to become active participants in maintaining their own health and medical care. The first Planetree Health Resource Center opened in 1981. A range of services provides access to reference assistance, clipping files, lecture series, publications, support groups, and an on-site bookstore (Cosgrove, 1991).

A program with greater longevity is Overlook Hospital in Summit, New Jersey. Over ten years old, the consumer health library serves a two-county area, contains 2,000 books, hundreds of pamphlets, twenty-five journal subscriptions, and 1,500 vertical files. About two-thirds of the users of the service were hospital staff (64 percent) and about one-third were telephone/walk-in patrons (36 percent). Moeller (1991) has reported that an important outcome of the Overlook experience was the realization that the service could survive with a reduced number of journals.

Compared to the number of hospitals in the United States, only a small percentage has expanded library services to include patients or families of patients. Competition in the health care environment

has resulted in single institutions providing services as compared to the library networks of the late 1970s and 1980s.

ACADEMIC HEALTH SCIENCES LIBRARIES

Clientele of academic health sciences libraries have traditionally been students, faculty, and researchers, and academic collections were developed to support the curriculum, clinical research, and practice. Model projects stemming from health sciences libraries during the 1980s—networking public libraries with academic medical libraries—included CHIRS, based at McGoogan Library of Medicine at the University of Nebraska at Omaha (Reidelbach, 1991); MEDINFO, based at the Harley E. French Library of the Health Sciences in Grand Forks, North Dakota; and Healthnet, an outreach program of the University of Connecticut Health Center Library (Arcari & Richetelle, 1991).

During a ten-month period in 1992, information services librarians at the University of Illinois at Chicago sampled patrons seeking health information. The purpose of this pilot project was to test a survey instrument and to capture data on who was asking these questions, whether or not requesters were being referred to LHS and by whom; the general nature of the request; and whether or not patrons had consulted other libraries or agencies prior to contacting LHS. More than 25 percent had consulted other resources prior to coming to LHS. Half of the requests were related to diseases or medical conditions, and about one-fourth were related to specific procedures, therapy, or tests.

Most academic CHI programs have been demonstration projects; once outside funding stopped, services were curtailed. Few projects were based on market or service research. Although numbers were collected to illustrate volume of activity, further analysis was not conducted.

LIBRARY NETWORKS AS PROVIDERS OF CONSUMER HEALTH INFORMATION

Library networks thrived during the late 1970s to mid-1980s. Attempts were made to link hospital libraries to medical centers. Public libraries and hospital libraries agreed informally to work together to serve clients. Multitype library consortia were sharing resources and extending collections to meet common resource goals. Newer CHI programs are structurally based on the models examined in 1980 by Raven Systems & Research, Inc.

This study, known as the Raven Study (1982), was funded by a contract awarded by the Center for Health Promotion and Education, Centers for Disease Control, to investigate library/health

education networking as a means for improving the availability and use of health information and health promotion resources and services. The long-range goal of the project was to identify, describe, and facilitate the development of state and local library networks and resources supportive of better services to library staff, health workers, and consumers. Overall objectives of the project were accomplished by examining ten programs in different settings.

The sites represented diverse geographic, organizational, and clientele characteristics. Information networks in cities on both coasts, with population ranges from 175,000 to 2.8 million were included. Part of this study assessed "leaderless" networks and consortia. Although individual members were often doing interesting work, leaderless networks lacked an ongoing systematic planning process. Final reports submitted in 1982 revealed that health-related ready reference questions were most likely to be disease related (60-80 percent) and quite specific. Women were far more likely to use the library for health-related purposes than men. Of the ten projects examined, four received initial LSCA (Library Services and Construction Act) funding. Four others were embedded in health care delivery systems, and one project was funded locally. Even when projects were primarily funded by grant monies, the parent institution had considerable influence over what funds were applied for and how those funds were ultimately used. By far the largest expenditures were for personnel. Average costs for personnel were \$175,697, and the average costs for acquisitions were \$39,011. Daily activities were hard to document since many were vested in a single person.

The greatest weakness of all the library networks studied was the lack of a broad base of cooperation. None developed a viable ongoing relationship with public and private health agencies. Time was also a serious constraint in the development of cooperative arrangements; and benefits to the library were not readily apparent. Consequently, nonlibrary network development received very little attention. Professional relationships must be developed and institutionalized. Public health agencies were involved with three of the programs; private agencies informally with four; projects which had public libraries as a central component (CHIPS, CHIN, Tulsa) were more likely to be involved informally with private agencies, such as the American Cancer Society. AHEC (Area Health Education Center) projects did have formal ties to physicians and physicians' groups, and physicians were involved on an advisory basis in other projects.

The Summary Report described a "Utopian Health Information Network" having five components:

1. Libraries supporting health professionals and the public are the major component of the "Utopian Network." These libraries are linked to one another using all the technology of library services,

including computerized database searching and preparation of union lists. Health information should be arranged in a hierarchial structure so that a patron entering the Network at the public library level has immediate access to health information whatever level is needed.

2. Formal agreements comprise a primary aspect of the "Utopian Network" (to ensure compliance without dependency).
3. Shared operating procedures which would allow any librarian at any point in the network access to the entire network. Private physicians have two roles in the network. First, they serve in a monitoring and advisory capacity to health information providers, reviewing resources and assisting libraries in the assessment process. "Second, they benefit by having health information providers as a referral source. Within the Utopian Network, the private physician can refer patients to a wide variety of supportive elements, depending on the patient's needs."
4. Schools and educational institutions should train librarians to be better providers of health information "through formal classes and workshops. They should conduct research aimed at discovering trends and improving practice in librarianship."
5. Public schools have the job of ensuring that students are aware of the Utopian Network and teaching them how to use it (Raven Systems & Research, Inc., 1982, pp. 23, 24).

Raven projects were surveyed in January 1993 to see if programs were still in existence, whether organization and governance had changed, and what cooperative arrangements had been extended to the community. Sites studied, their location, and current status are included in Table 1.

Follow-up on the Raven Study after ten years proved difficult. People involved with the original projects have since left. Telephone interviews were able to capture the current status and whether programs had evolved or been absorbed into other services. For most, services declined after the funding stopped. Factors cited as contributing to the demise of the programs included limited funding, reduced personnel, and downsized collections. Professional librarians at two sites noted the increased availability of CHI as one reason why services were discontinued. Kaiser-Permanente is one of two sites studied by Raven Systems which continues to provide a full range of health information services to Kaiser patients, their families, and the walk-in public. The Tulsa City-County Library is the other. Four of the sites were absorbed into other services or structures, and four no longer exist.

TABLE 1
RAVEN STUDY SITES

<i>Project</i>	<i>Location</i>	<i>Existence (Y/N/A)*</i>
CHIN (Consumer Health Information Network)	Mt. Auburn Hospital Cambridge, MA	N
CHIPS (Consumer Health Information Program and Services)	Los Angeles County Harbour Los Angeles, CA	A
The Health Library	Kaiser-Permanente Medical Center Oakland, CA	Y
InfoHealth	Case Western Reserve University Cleveland, OH	N
The North Dakota AHEC Library System	Harley E. French Library Grand Forks, ND	A
CHIC (Consumer Health Information Consortium)	Onadaga County Public Library Syracuse, NY	A
Health Information Service	Tulsa City-County Public Library Tulsa, OK	Y
Statewide Outreach Program	The University of New Mexico Medical Center Library Albuquerque, NM	A
School of Public Health Library	The University of Pittsburgh School of Public Health Pittsburgh, PA	N
Library/Learning Resource Center Network	The North Carolina AHEC Program Chapel Hill, NC	N

*Y = Still in existence/ N = No longer in existence/ A = Absorbed into other services or structures

PROBLEMS DELIVERING INFORMATION

The provision of health information in Ontario public libraries and the problems experienced by librarians was discussed by Marshall in 1991. Findings included a significant proportion of user enquiries related to health in public libraries. Over half the libraries surveyed (56 percent) reported an increase in the last three years. Problems

faced by Canadian public librarians in dealing with health requests include the sensitive nature of the reference interview, inadequately trained librarians, and inadequate resources. In the Marshall study, 94 percent of the librarians participating in the study stated they relied extensively upon on-the-job experience as a basis for providing health information service.

Public libraries participating in the University of Illinois at Chicago study also reported difficulty in handling the sensitive nature of health requests (60 percent). Others had problems with the medical vocabulary, and about one-third cited a lack of appropriate resources as a problem in delivering health information. Approximately 75 percent of the UIC sample said librarians are trained to respond to health requests, and that they are trained by senior staff librarians.

Other problems encountered in delivering health care information via libraries include little cooperation among libraries in sharing consumer resources, inadequate collections, and bibliographic control (health materials such as pamphlets or fact sheets); collections can easily become dated as advances in medicine constantly change. Professional medical literature continues to be used to satisfy consumer requests even though these resources are written for a different level of understanding.

Inadequate collections have also been cited as a problem in disseminating consumer information related to AIDS (SantaVicca, 1987). Although background information is frequently found in books, decisions related to health care are probably not going to be found in published books given printed information is from one-to-three years old by the time it is published. Proportionately, public libraries seem to spend more money on books than journal literature. Although published guidelines for referral are nearly nonexistent, results of the UIC LHS sample of public libraries in the United States indicate that large public libraries routinely refer patrons to other libraries or agencies in responding to health requests that cannot be satisfied within the library.

Cooperative planning among public, academic, and hospital libraries and community health organizations has been discussed (Defoe, 1991; Arcari, 1991; Reidelbach, 1991). Every consumer health service or health information network has developed core resources. One of the most recent was compiled by Arcari and Richetelle (1991).

FUTURE TRENDS

The pressing need for health information is heightened by the absence of a coordinated national health information dissemination system. If the consumer or patient is not directed to existing resources, information centers and clearinghouses will be underutilized, and

the patient's ability to make informed decisions will be affected. Current awareness resources most often are stored in vertical files with limited access. Like government documents, these items normally are not retrievable through the library's online catalog.

Public libraries are conveniently positioned to disseminate health information to the consumer seeking information related to health and wellness. Hospital libraries are closest to the physician/patient encounter and present an ideal environment to provide resources and services to patients and their families. In the 1980s, multitype library networks limited resource sharing to interlibrary loans of the printed page. Libraries collecting pamphlets and other peripheral resources restricted the sharing of these resources to primary clientele. Referrals were based on established relationships with few specified guidelines. Today few libraries routinely search health information databases as part of a reference protocol when assisting patrons needing information regarding treatment options. In the 1990s, libraries must rethink cooperation and extend collaborative relationships to other health care agencies and professional organizations. Shared database development will provide more efficient and expanded access. Databases like *PDQ* are already available through the Internet. Campus computing systems in academic centers make hundreds of resources available (through menuing devices, such as Gopher) to every person working in an academic environment. Access to information, however, does not necessarily translate to "item in hand."

Pilot studies reveal that public libraries are doing a commendable job serving the public's interest in health care. Many subscribe to health care newsletters; the majority subscribe to popular professional journals such as *JAMA (Journal of the American Medical Association)*, *New England Journal of Medicine (NEJM)*, *Science*, and *Nature*. Even in the economically depressed early 1990s, large public libraries added to their health collections. In analyzing health-related requests, a majority of the patrons seeking health information in public libraries are high school or college students working on assignments and adult users seeking personal health information. Fewer businesses, researchers, or health professionals seek such information in public libraries, indicating they may have other avenues for locating this information. Public and hospital libraries are extending service not only to walk-in patrons but also through active telephone service. During a six-month period in 1992, the Buffalo and Erie County Public Library (Science and Technology Department) received 3,358 telephone reference calls. Of that number, 22 percent (730) were medical or health related.

Library communication networks exist with different administrations and dissimilar geographic boundaries. The Centers for the

Blind and Physically Handicapped, administered by the Library of Congress, do not geographically coincide with the National Network of Libraries of Medicine. Government-funded AIDS and geriatrics programs are also regionally based with similar education and information goals but have dissimilar boundaries. The NLM has successfully administered the National Network of Libraries of Medicine (NNLM), distributing information about their products (e.g., MEDLINE) and services for more than twenty-five years. Using this network, CHI could be disseminated through 142 resource libraries in major medical centers to more than 3,500 primary-access libraries in hospitals and health care facilities.

Strengths and weaknesses identified with the Raven demonstration projects either have not been communicated or have been ignored. The Utopian Health Information Network described has never materialized. The greatest weakness of all the projects studied was the lack of broad-based cooperation. Libraries cooperate with libraries, but they have not successfully networked to other health agencies and organizations. Leadership and formal agreements were key factors identified by this study, yet programs remain undervalued by administrators.

Information is a commodity and should be analyzed as such by libraries. The *Medicare Provider Reimbursement Manual* provides a list of approved accrediting organizations and activities. Although approved educational programs include nearly every imaginable profession (from physical therapy and medical technology to nursing), there are no health information programs listed, nor is there an approved organization such as the Medical Library Association or American Society for Information Science listed.

The potential for librarian involvement in the dissemination of CHI is dependent on the vision of the institutions where they work and their potential to see beyond the library as an organization. Creative services will evolve as libraries change their breadth and scope to encompass university and hospital outreach goals. Unlike the demonstration projects studied by Raven Systems, libraries need to foster and maintain links to community and state organizations producing and distributing information resources. Libraries need to take a proactive approach to collecting and disseminating information generated as a result of Healthy People 2000.

Access to information means more than providing the bibliographic citation. Librarians are trained to locate information resources. To comply with the consumer's demand for health information, a logical role for librarians is to develop databases comprised of important segments of documents (abstracts, summaries, results) to begin to filter the important aspects of the literature.

Librarians engaged in research projects with their health professional counterparts can change the way health information is valued. Expanded networks, improved communication, perception of librarians, and applications of information technology will virtually influence change in the ways libraries disseminate health information.

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APPENDIX

CURRENT AWARENESS TECHNIQUES AND RESOURCES

Since 1985, resources have been designed to communicate information about risk factors and lifestyle. Documentaries air regularly on television, and commercials broadcast health messages. Other resources available to the public include newsletters, newspaper health sections, information clearinghouses (government and nongovernment), consensus conferences, self-help groups, and publications generated by the National Center for Health Statistics (NCHS) and the Office of Disease Prevention and Health Promotion (ODPHP).

Newsletters. Those designed to raise the health consciousness of the consumer include: the *Harvard Medical Letter*, the University of California at Berkeley *Wellness Letter*, the *Mayo Clinic Health Letter*, *Tufts University Diet and Nutrition Newsletter*, and *Prevention Report*, a publication of the Public Health Service (PHS). Newsletters communicate information designed for special populations. More than twenty newsletters have been identified that relate to the needs of the elder consumer. *AFB News* carries information on resources and assistive devices for the blind and physically handicapped. *CANE Exchange* reports services responsive to elder abuse and *Medication Trends for Older Adults* communicates developments in medication management, biotechnology, and pharmaceutical innovation from thirty research-based pharmaceutical companies. *Elder Care News* (published by the University of Maryland at Baltimore School of Pharmacy) synthesizes literature related to medications, nutrition, and oral health of the elderly; the *AARP Bulletin* carries articles about health insurance and legislation. Newsletters of other advocacy groups, such as United Seniors (*United Seniors Health Report*) and the Alzheimer's Association (*AD Newsletter*), serve as vehicles to disseminate information and services.

Newspaper Health Sections. The *Washington Post* Tuesday Health Section has been published regularly since October 10, 1984. This section carries news on health care issues (e.g., "Shopping for a Health Care Plan," November 17, 1992, p. 17) and includes a weekly calendar of activities, articles on health care topics, vital statistics, and treatment trends. Information contained in weekly health sections are sometimes accessible via database vendors, such as LEXIS, DATATIMES, and DIALOG. Libraries can also access newspaper information via VU-TEXT. Unfortunately, the printed "health" section of the *Washington Post* is not available as a separate subscription.

Information Clearinghouses. One of the newest national clearinghouses is NAIC (National AIDS Information Clearinghouse). In addition to maintaining a hotline (1-800-AIDS), this organization monitors a number of AIDS-related organizations—e.g., the Minority Task Force on AIDS, Mothers of AIDS Patients (MAP), National Association of People with AIDS, and the National Coalition of Gay Sexually Transmitted Disease Services. NAIC also produces resource guides dealing with such topics as AIDS and deafness. Other national clearinghouses include the Cancer Information Service, the National Rehabilitation Information Center, the National Information Center for Orphan Drugs & Rare Diseases; the National Diabetes Clearinghouse; the National Clearinghouse for Alcohol & Drug Abuse; the National Digestive Diseases Information Clearinghouse; and the Clearinghouse on Health Indexes.

Consensus Conferences. These conferences and their subsequent reports are designed to produce accessible and readily understandable consensus recommendations that summarize the implications of existing research evidence. The need for such summaries has been facilitated by the burgeoning scientific literature; the inadequacy of traditional journal articles as sources for direct decisions; awareness that a significant proportion of care is inappropriately provided; a shift from expected benefits to actual benefits; demands by third-party monitors for succinct recommendations about appropriate practice; and pressure from the public for increased input to medical and technological decision making. Consensus recommendations are used as the criteria for evaluation and appraisal aimed at changing practice behavior, making administrative decisions on resource allocation, or defining research protocols. Lomas discusses current methodologies, a framework for evaluating the consensus process, and controversies surrounding "resolution of conflict" (Lomas, 1991). Consensus conferences are included in the MEDLINE database as a publication type and can be searched with a heading qualified by (pt).

Clinical Alerts. Clinical alerts are released periodically and are available through an NLM database called ALERT. The scope of the database includes research findings from NIH-funded clinical trials and presently contains about eight 1-2 page summaries. Full-text or bibliographic information is available to MEDLINE and GRATEFUL MED subscribers.

Electronic Tools. Databases, such as the NLM's *DIRLINE* and the NCI's *PDQ* provide useful directories (e.g., health care associations and cancer experts). *DIRLINE* entries include service descriptions, hours of operation, as well as toll-free telephone numbers and other pertinent information. *PDQ (Physician's Data Query)* is the National Cancer Institute's (NCI) database which provides information on cancer treatment, research protocols, and a directory of physicians and organizations involved in cancer care. NCI also maintains a toll-free telephone service (1-800-4-CANCER). The *FDA's Bulletin Board* provides information on new drugs under development as well as information about food and drug recalls. *VU-TEXT* (covering newspapers 1-800-258-8080) and CD-ROM products, such as *Health Index Plus*, contain full-text articles and consumer-oriented summaries. The *AIDS Book Review Journal* made its debut in March 1993. Accessible through the Internet, it allows viewers to browse pertinent resources about AIDS, safer sex, and sexually transmitted diseases (LISTSERV@UICVM).

Self-Help Groups. At least two self-help clearinghouses profile support organizations and make them accessible. These are the National Self-Help Clearinghouse (City University of New York, 212-840-1259) and the Self-Help Clearinghouse of Greater Washington (Mental Health Association of Northern Virginia, Falls Church, VA, 703-536-4100).

The Office of Disease Prevention and Health Promotion. The ODPHP, the information support branch for the Public Health Service, enhances the public's access to information and works with national and local organizations having common goals. In addition to publishing a series of healthfinders (bibliographies related to current topics in health), the ODPHP provides lists of clearinghouses and toll-free numbers for health information.

The National Center for Health Statistics. The NCHS, part of the Centers for Disease Control, is the only federal organization established specifically to collect and disseminate data on health in the United States. NCHS publications provide statistical validity to health studies including the

ongoing National Health Interview Survey. The National Health Interview Survey is a continuing nationwide survey of the U. S. civilian noninstitutionalized population conducted in households. Each week a probability sample of households is interviewed by trained personnel of the U. S. Bureau of the Census to obtain information about the health and other characteristics of each living member of the sample. The sample is composed of 36,000 to 46,000 households including 92,000 to 135,000 persons (depending on the year). Publications are inexpensive and usually found in government document sections of public or academic libraries.

National Technical Information Service. The NTIS supplies technical reports and analyses from foreign national and local government agencies. Foreign reports now comprise 20 percent of the NTIS collection. NTIS distributes federally-generated computerized datafiles, databases, and software; it is the licensing agency of U. S. patents, and manages the Center for the Utilization of Federal Technology. About 70,000 items of information from U. S. and foreign governments are added to the collection annually. Individuals seeking the latest technical reports may subscribe to one of NTIS' current awareness bulletins. The NTIS Bibliographic Database is searchable through major online vendors, such as DIALOG, ORBIT, and STN. NTIS Customer Services can be reached at 703-487-4660 during business hours.

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